

# Appendices



## Appendix 1: International guidelines on antiretroviral therapy and prophylaxis 2000-2010

### **2000: New data on the prevention of mother-to-child transmission of HIV and their policy implications. Conclusions and recommendations**

*All the regimens that have been shown to be effective in controlled clinical trials can be recommended for use in MTCT-prevention programmes in such settings. These regimens include zidovudine alone, zidovudine plus lamivudine, and nevirapine alone. There are no longer any justification to restrict use of any of these regimens to pilot project or research settings. [1]*

### **2004: Antiretroviral drugs for treating pregnant women and prevention HIV infection in infants: Guidelines on care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings.**

*“Women who need ARV treatment for their own health should receive it in accordance with the WHO guidelines on ARV treatment. HIV-infected pregnant women who do not have indications for ARV treatment, or do not have access to treatment should be offered ARV prophylaxis to prevent MTCT using one of several ARV regimens known to be safe and effective:*

- *ZDV from 28 weeks of pregnancy plus single-dose NVP during labour and single-dose NVP and one-week ZDV for the infant.*
- *Alternative regimens based on ZDV alone, short-course ZDV + 3TC or single-dose NVP alone are also recommended.” [2]*

### **2006: Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants: towards universal access: recommendations for a public health approach. 2006 version**

*ART for pregnant women is recommended for [3]:*

- *All women in clinical stage 4 irrespective of the CD4 cell count;*
  - *Women in clinical stage 3, with the CD4 <350 cells/mm<sup>3</sup> count, if available; if the CD4 cell count is not available, all women in stage III should be treated;*
  - *Women in clinical stage I and 2 with a cell count of CD4 <200 cells/mm<sup>3</sup>.*
- *The preferred first-line regimen for antiretroviral therapy for pregnant women is AZT + 3TC + NVP*

*ARV regimen for women who do not have indications for ART, consisting of AZT starting from 28 weeks of pregnancy (or as soon as possible thereafter); AZT and 3TC + Sd-NVP intrapartum; and AZT and 3TC postpartum for seven days for women, and for infants Sd-NVP and AZT for one week*

- *The NVP dose can be given to an infant up to 72 hours after childbirth but should preferably be given as soon as possible after delivery*

## **2010: Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants: recommendation for a public health approach. 2010 version**

### *Key recommendations [4]:*

- 1. Earlier antiretroviral therapy (ART) for a larger group of HIV-positive pregnant women to benefit both the health of the mother and prevent HIV transmission to her child during pregnancy.*
- 2. Longer provision of antiretroviral (ARV) prophylaxis for HIV-positive pregnant women with relatively strong immune systems who do not need ART for their own health. This would reduce the risk of HIV transmission from mother to child.*
- 3. Provision of ARVs to the mother or child to reduce the risk of HIV transmission during the breastfeeding period. For the first time, there is enough evidence for WHO to recommend ARVs while breastfeeding.*

### *Main revisions:*

- 1. start lifelong ART cd4 < 350*
  - 2. Start ARV prophylaxis 14 weeks: two options: 1) daily AZT for the mother and infant prophylaxis for six weeks after birth and continued until the end of breastfeeding period. 2) a three drug regimen for the mother to take during pregnancy and throughout the breastfeeding period, as well as infant prophylaxis for six weeks after birth.*
  - 3. The use of ARVs to prevent HIV transmission from mother to baby during breastfeeding. Two options: 1) if a woman receives AZT during pregnancy, daily nevirapine is recommended for her child from birth until the end of the breastfeeding period. 2) If a woman received a three-drug regimen during pregnancy, a continued regimen of three-drugs prophylaxis is recommended for the mother until the end of the breastfeeding period.*
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- 1. World Health Organization: New data on the prevention of mother-to-child transmission of HIV and their policy implications. Conclusions and recommendations. WHO Technical consultation on behalf of the UNFPA/UNICEF/WHO/UNAIDS Inter-Agency Task Team on Mother-to-Child Transmission of HIV. Geneva, 11-13 October 2000. Geneva; 2001*
  - 2. World Health Organisation: Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants. Guidelines on care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings. Geneva; 2004*
  - 3. World Health Organisation: Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants: towards universal access: recommendations for a public health approach. 2006 version. Geneva; 2006*
  - 4. World Health Organisation: Antiretroviral drugs for treating pregnant women and preventing HIV infections in infants: recommendations for a public health approach. 2010 version. Geneva; 2010*



## Appendix 2: International guidelines on infant feeding 1992-2010

### **1992 statement by WHO and UNICEF:**

*“Where infectious diseases and malnutrition are the main cause of infant deaths and the infant mortality rate is high, breastfeeding should be the usual advice given to pregnant women including those who are HIV infected. This is because their baby's risk of HIV infection through breast milk is likely to be lower than the risk of death from other causes if it is not breastfed.” [1]*

### **1997 statement by WHO, UNICEF, and UNAIDS:**

*“When children born to HIV-infected women can be assured of uninterrupted access to nutritionally adequate breast milk substitutes that are safely prepared and fed to them, they are at less risk of illness and death if they are not breastfed. However, when these conditions cannot be met, in particular in environments where infectious diseases and malnutrition are the primary causes of death during infancy, then artificial feeding substantially increases children's risk of illness and death. The policy objective must be to minimize all infant feeding risks and to urgently expand access to adequate alternatives so that HIV-infected women have a range of choices. The policy should also stipulate what measures are being taken to make breast milk substitutes available and affordable; to teach the safest means of feeding them to infants; and to provide the conditions which will diminish the risks of using them.” [2, 3]*

### **2000 Statement by WHO Technical consultation on behalf of the UNFPA/UNICEF/WHO/UNAIDS Inter-Agency Task Team on Mother-to-Child Transmission of HIV (WHO 2001):**

*“When replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS), avoidance of all breastfeeding by HIV-infected mothers is recommended. Otherwise, exclusive breastfeeding is recommended during the first months of life.”*

*“All HIV-infected mothers should receive counselling, which includes provision of general information about the risks and benefits of various infant feeding options, and specific guidance in selecting the option most likely to be suitable for their situation. Whatever a mother decides, she should be supported in her choice. Assessments should be conducted locally to identify the range of feeding options that are acceptable, feasible, affordable, sustainable and safe in a particular context.” [4]*

The infant feeding options for HIV-infected mothers [4]:

- exclusive breastfeeding
- exclusive formula feeding
- exclusive home-modified animal milk
- wet-nursing by an HIV-negative woman
- expressing and heat-treating breast milk
- breast milk banks

## **2006: HIV and infant feeding: Update based on the Technical consultation held on behalf of the Inter-Agency Task Team (IATT) on Prevention of HIV Infection in Pregnant Women, Mothers and their Infants**

*“Exclusive breastfeeding is recommended for HIV-infected women for the first six months of life unless replacement feeding is acceptable, feasible, affordable, sustainable and safe for them and their infants before that time.”*

*“When replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV-infected mothers is recommended.” [5]*

- early cessation is no longer recommended
- abrupt cessation is no longer recommended
- home-modified animal milk is no longer recommended

## **Guidelines on HIV and infant feeding 2010. Principles and recommendations for infant feeding in the context of HIV and a summary of evidence**

### *Main principles:*

*Setting national or sub-national recommendations for infant feeding in the context of HIV National or sub-national health authorities should decide whether health services will principally counsel and support mothers known to be HIV-infected to either:*

- *breastfeed and receive ARV interventions,*

*or,*

- *avoid all breastfeeding,*

*as the strategy that will most likely give infants the greatest chance of HIV-free survival.*

*The mother should also be informed about feeding alternatives.*

### *Main recommendations:*

- *Mothers known to be HIV-infected should receive lifelong ART or ARV prophylaxis to reduce HIV transmission through breastfeeding*
- *HIV-infected mothers should EBF for the first six months, introduce appropriate complementary foods and then continue breastfeeding for the first 12 months of life*
- *when stopping breastfeeding it should be done gradually within one month*
- *HIV-infected mothers should only give commercial infant formula milk as replacement feed if the AFASS conditions are met [6]*

1. World Health Organization, UNICEF: **Global programme on AIDS. Consensus statement from the WHO/UNICEF consultation on HIV transmission and breastfeeding.** *Wkly Epidemiol Rec* 1992, **67**:177-179.
2. World Health Organization, UNAIDS, UNICEF: *HIV and infant feeding. Guidelines for decision-makers.* Geneva; 1998
3. World Health Organization, UNAIDS, UNICEF: *HIV and infant feeding. A guide for health-care managers and supervisors.* Geneva; 1998
4. World Health Organization: *New data on the prevention of mother-to-child transmission of HIV and their policy implications. Conclusions and recommendations.* WHO Technical consultation on behalf of the UNFPA/UNICEF/WHO/UNAIDS Inter-

*Agency Task Team on Mother-to-Child Transmission of HIV. Geneva, 11-13 October 2000. Geneva; 2001*

5. World Health Organization, UNICEF, UNAIDS, United Nations Population Fund: *HIV and Infant Feeding: Update based on the technical consultation held on behalf of the Inter-agency Team (IATT) on Prevention of HIV Infections in Pregnant Women, Mothers and their Infants, Geneva, 25-27 October 2006. Geneva; 2006*
6. World Health Organisation, UNAIDS, UNFPA, UNICEF: *Guidelines on HIV and infant feeding 2010. Principles and recommendations for infant feeding in the context of HIV and a summary of evidence. Geneva; 2010*





### Appendix 3: Overview of quantitative and qualitative methodologies

	<b>Quantitative</b>	<b>Qualitative</b>
Assumptions about reality	Objective truth	Multiple, subjective realities
How knowledge is produced	Not interact with the informants so to influence them	Researcher and informants interactive and inseparable: researcher as the survey instrument
Way of reasoning	Deductive: test predefined hypothesis	Inductive: to discover new concepts/hypothesis/theories
Research questions	Confirmatory	Exploratory
Research design	Strictly planned	Emergent
Sampling	Probability sampling	Purposive sampling
Data analysis	Numerical descriptive, statistical hypothesis testing	Textual analysis
Truth value (measured what we set out to measure)	Internal validity	Credibility
Applicability - to other contexts	External validity / generalizability	Transferability
Consistency (repeated findings if research replicated)	Reliability	Dependability
Neutrality (findings affected by personal interests and biases)	Objectivity	Conformability
Main strengths	<ul style="list-style-type: none"> <li>• may generalize findings</li> <li>• useful studying large numbers</li> <li>• assess cause-effect relationship more credible</li> </ul>	<ul style="list-style-type: none"> <li>• useful for describing complex phenomena</li> <li>• peoples own understanding and experience of phenomena</li> <li>• context is identified</li> </ul>
Main weaknesses	<ul style="list-style-type: none"> <li>• the research may not reflect local understanding</li> <li>• may miss out of phenomena occurring due to focus of hypothesis testing rather than generalisation</li> </ul>	<ul style="list-style-type: none"> <li>• may not be generalizable</li> <li>• may have lower credibility among stakeholders</li> <li>• time consuming</li> <li>• influence by the researcher</li> </ul>

[1, 2]

1. Dahlgren L, Emmelin M, Winkvist A: *Qualitative Methodology for International Public Health*. Print och Media, Umeå University; 2004.
2. Johnson RB, Onwuegbuzie AJ: **Mixed method research: a research paradigm whose time has come**. *Educational Researcher* 2004, **33**:14-26.



## Appendix 4: Informed consent form

### Survey

Title of study: The role of male partners and mothers-in-law in the prevention of mother-to-child transmission of HIV

This form gives you information about the study in which you are being requested to participate in. To make sure that you have all the facts about the study you must read this form or have someone read it to you. If you agree to participate in the study you should sign this form or put a mark in the space on the form if you cannot sign. You will get a copy of this form to keep. Discuss any unclear section on this form with the Project Staff. If you feel that you do not want to take part you are free not to participate in the study and your refusal will in no way influence your care from the health staff or members of the Project Staff.

This study is being conducted by Kilimanjaro Christian Medical College / Tumani University, Tanzania and Centre for International Health, University of Bergen.

#### **My rights as a research volunteer:**

Before I can decide whether or not to volunteer for this study, I must understand its purpose, how it may help me and any risks to myself and what is expected of me if I decide to participate in this study. This process is called informed consent.

This consent form gives me information about the study which will also be discussed with me. Once I understand the study and agree to participate, I will be asked to sign this consent form. I understand that my participation in this study is entirely voluntary. I may decide to withdraw from the study at any stage. Such a decision will not affect my medical care or possible participation in future research studies in any way.

The purpose of the study is to obtain information that will be used to understand the factors that influence female participation in the prevention of mother-to-child transmission of HIV programme. Interviews will last about one hour.

#### **Study procedures:**

I understand that if I decide to participate in the study, I will be asked some questions about health.

#### **Risks to me:**

I understand that there are no risks to me, except for the temporary anxiety that may arise from the questions to be asked and for the time that I will spend here.

#### **Potential benefits to me:**

There are no immediate benefits from this study. However, I understand that the results of the study will be used to improve the delivery of health services, which will be of benefit to my child(ren) and to me.

#### **Costs or payments to me:**

There are no costs or payments to me.

**Confidentiality:**

I understand that the information that I give shall be confidential. I will not be personally identified in any publication or presentation about this study.

**Respondents consent:**

..... has described to me what is going to be done, the risks, hazards and benefits involved. I understand that my decision to participate in this study or not to do so will not alter my usual health care. In the use of the information generated from this study such as publications, my identity will remain anonymous. I am aware that I may withdraw from this study any time.

I understand that by signing this consent form, I do not waive my legal rights nor does it relieve investigators of liability but merely indicates that I have been informed about the research study in which I am voluntarily agreeing to participate.

Respondent’s Name:.....

Volunteer's Signature or Thumbprint:.....

Witness’ Name..... Signature:.....

Date:..... ID No. [ ][ ][ ][ ]

Swahili version: Informed consent

**Utafiti**

**Fomu ya idhini**

Jina la utafiti: Jukumu la mwanaume na mama mkwe katika kuzuiwa maambukizi ya Virusi vya Ukimwi(VVU) kutoka kwa mama kwenda kwa mtoto.

Fomu hii ya idhini itakupa maelezo kuhusu utafiti huu. Unatakiwa kuisoma kwa makini fomu hii au kusomewa na mtu mwingine kama huwezi kusoma kabla ya kukubali kushiriki katika utafiti huu. Utapewa ufafanuzi zaidi na watafiti na iwapo utakubali kushiriki kwenye utafiti huu, utaombwa kutia sahihi kwenye fomu hii. Kama huna uwezo wa kuandika utaweka alama ya kidole gumba katika nafasi utakayo onyeshwa katika fomu hii. Pia utapewa nakala ya fomu hii iliyotiwa sahihi yakoau alama ya kidole gumba.

Iwapo hutapenda kushiriki kwenye utafiti huu unayo hiari ya kukataa bila ya kupoteza haki yako ya kupata huduma za kawaida za matibabu kutoka kwa wahudumu wa afya au watafiti wa mradi huu. Utafiti huu unaendeshwa kwa pamoja kati ya Chuo kikuu cha KCMC na Kituo cha Afya ya jamii, Chuo Kikuu cha Bergen.

**Haki yangu kama mshiriki katika utafiti:**

Kabla sijaamua kushiriki kwenye utafiti huu, nahitaji kuelewa madhumuni yake, faida au hatari zozote kwangu na wajibu wangu iwapo nitaamua kushiriki kwenye utafiti huu. Mchakato huu unaitwa idhini ya hiari.

Fomu hii ya idhini imenipatia maelezo kuhusu utafiti huu ambao pia tutajadiliana pamoja na watafiti. Baada ya majadiliano hayo na iwapo nitakubali kushiriki katika utafiti huu, nitahitajika kuweka sahihi au alama ya kidole gumba katika fomu husika. Najua kuwa ushiriki wangu kwenye utafiti huu ni wa hiari yangu. Ninao uwezo wa kuacha kuendelea na utafiti huu wakati wowote na uamuzi wangu hautaniondolea haki yangu ya kupatiwa matibabu ya kawaida au kushiriki katika tafiti zingine .

Dhumuni kuu la utafiti huu ni kuwawezesha watafiti kujua visababishi vinavyo wafanya wanawake kushiriki katika mikakati ya kuzuia maambukizi ya Virusi vya Ukimwi (VUU) kutoka kwa mama kwenda kwa mtoto. Usahili utachukua wastani wa dakika 60 (saa moja).

**Utaratibu wa utafiti:**

Najua kuwa nikikubali kushiriki kwenye utafiti huu nitaulizwa maswali.

**Tahadhari:**

Najua kuwa hakuna hatari yoyote kwangu katika kushiriki utafiti huu. Naweza kupata wasiwasi, huzuni au kujisikia vibaya kutokana na baadhi ya maswali nitakayoulizwa na muda nitakaotumia kwa ajili ya usaili.

**Faida:**

Hakuna faida ya moja kwa moja katika kushiriki kwenye utafiti huu. Hata hivyo natambua kuwa matokeo ya utafiti huu yatasaidia kuboresha huduma za afya ya mama na mtoto. Hii itakuwa na faida kubwa kwa watoto na akina mama wote.

**Gharama:**

Hakuna gharama utakayoingia kwa kuamua kushiriki kwenye utafiti huu.

**Usiri:**

Najua kuwa taarifa nitakazozitoa zitahifadhiwa kwa usiri mkubwa. Jina langu halitatumika wakati wowote wala mahali popote. Utambulisho wangu hautajulikana wakati taarifa za utafiti huu zitakapotolewa kwenye mikutano au kutangazwa au kuchapishwa.

**Idhini ya mshiriki:**

..... amenipa maelezo yote kuhusu madhumuni, tahadhari na faida za kushiriki kwenye utafiti huu. Najua kuwa ushiriki au kutokushiriki kwenye utafiti huu hakutaniondolea haki yangu ya kupatiwa matibabu ya kawaida. Matokeo ya utafiti huu yatakapotolewa katika mikutano au machapisho utambulisho wangu utabakia kuwa ni siri. Natambua kuwa ninayo haki ya kujitoa kwenye utafiti huu wakati wowote. Natambua kuwa kwa kuweka sahihi katika fomu hii, sijapoteza haki zangu za kisheria wala kuwaondolei watafiti jukumu lao la kunilinda na hatari zinazoweza kutokana na utafiti huu. Naweza sahihi kwa sababu nimepewa maelezo yote muhimu na mimi nimekubali kushiriki kwa hiari yangu mwenyewe

Jina la mshiriki:.....

Sahihi au alama ya kidole gumba cha Mshiriki:.....

Jina la Shahidi..... Sahihi:.....

Tarehe:..... Namba ya Utambulisho. [ ][ ][ ][ ]

## Appendix 5: Survey

### Introduction

Hello, I come from Kilimanjaro Christian Medical College / Tumani University, Tanzania and Centre for International Health, University of Bergen, Norway. The title of study is: The role of male partners and mothers-in-law in the prevention of mother-to-child transmission of HIV. The purpose of the study is to obtain information that will be used to understand the factors that influence female participation in the prevention of mother-to-child transmission of HIV programme. The results of the study will be used to improve the delivery of health services. The information you give shall be confidential and you will not be personally identified in any publication or presentation about this study.

### PART 1

#### I. IDENTIFICATION

1. Date of interview	
2. Name of Interviewer	
3. ID Number	[ ][ ][ ]
4. Name of the clinic	[ ] Kibosho [ ] Marangu Hospital [ ] Mawenzi [ ] KCMC [ ] Majengo
5. Where do you live?	_____ Classification : [ ] rural [ ] urban
6. How old are you ( <i>completed</i> <i>years</i> )	_____ years

#### II. YOUR CHILD

Now I am going to ask you some questions about your youngest child.

7. When was the child born?	_____ date
8. How many other (than this child) children do you have?	_____ (number)
9. Where did you give birth to this child?	[ ] home [ ] health post _____ (name of post) [ ] hospital _____ (name of hospital) [ ] other, specify: _____



10. Who attended to you during birth?	<input type="checkbox"/> nurse/midwife <input type="checkbox"/> doctor <input type="checkbox"/> other, specify: _____
11. Did you attend antenatal clinic during this pregnancy?	<input type="checkbox"/> yes <input type="checkbox"/> no (skip to 15)
12. Where did you go for antenatal care?	<input type="checkbox"/> Kibosho <input type="checkbox"/> Marangu <input type="checkbox"/> Mawenzi <input type="checkbox"/> KCMC <input type="checkbox"/> Majengo <input type="checkbox"/> other, specify: _____
13. When did you have your first visit at the antenatal? ( <i>ask to see card</i> )	<input type="checkbox"/> first trimester <input type="checkbox"/> second trimester <input type="checkbox"/> third trimester
14. How many times did you attend antenatal care during your last pregnancy? ( <i>ask to see card</i> )	____ (number)
15. Do you breastfeed this child?	<input type="checkbox"/> yes (skip to 18) <input type="checkbox"/> no
16. If no, have you ever breastfed this child?	<input type="checkbox"/> yes <input type="checkbox"/> no (skip to 19)
17. For how long did you breastfeed?	_____ weeks
18. When did you start breastfeeding?	<input type="checkbox"/> within one hour after birth <input type="checkbox"/> after one hour, before 12 hours <input type="checkbox"/> after 12 hours, before 24 hours <input type="checkbox"/> after 24 hours, before 48 hours <input type="checkbox"/> within the second day <input type="checkbox"/> within the third day <input type="checkbox"/> after the third day
19. What did you feed the child during the <i>first three days</i> after birth? ( <i>tick all that apply</i> )	<input type="checkbox"/> breast milk <input type="checkbox"/> water <input type="checkbox"/> water and sugar <input type="checkbox"/> cows milk <input type="checkbox"/> formula milk <input type="checkbox"/> soft porridge <input type="checkbox"/> other, specify: _____
20. Have you <i>ever</i> given the child anything else than breast milk, even water or fruit juice?	<input type="checkbox"/> yes <input type="checkbox"/> no (skip to 23)
21. If yes, what did you give ( <i>tick all that apply</i> )	<input type="checkbox"/> water <input type="checkbox"/> water and sugar <input type="checkbox"/> fruit juice <input type="checkbox"/> cow milk <input type="checkbox"/> formula milk <input type="checkbox"/> soft porridge <input type="checkbox"/> mashed vegetables <input type="checkbox"/> mashed meat <input type="checkbox"/> other, specify _____
22. If yes, have you given it this last week?	<input type="checkbox"/> yes <input type="checkbox"/> no

23. At what age will you start (/did you start) giving your child other liquid food in addition to breastfeeding?	_____ months
24. At what age will you start (/did you start) giving your child other solid food in addition to breastfeeding?	_____ months

### III. SOCIO-DEMOGRAPHIC CHARACTERISTICS

25. What is your current marital status?	<input type="checkbox"/> single <input type="checkbox"/> divorced/separated <input type="checkbox"/> widower <input type="checkbox"/> cohabiting <input type="checkbox"/> married
26. If married, do you live with your husband?	<input type="checkbox"/> yes, all the time <input type="checkbox"/> yes, most of the time <input type="checkbox"/> yes, but only part of the year <input type="checkbox"/> no, visits only
27. What is your religion?	<input type="checkbox"/> protestant/ lutheran <input type="checkbox"/> catholic <input type="checkbox"/> muslim <input type="checkbox"/> other, specify: _____
28. What is your ethnic background?	<input type="checkbox"/> Chagga <input type="checkbox"/> Pare <input type="checkbox"/> Masai <input type="checkbox"/> other, specify: _____
29. How many completed years of schooling have you had? ( <i>exclude repeated years and pre-school</i> )	_____ years
30. What do you do for a living? ( <i>only tick one</i> )	<input type="checkbox"/> housewife <input type="checkbox"/> farmer <input type="checkbox"/> service <input type="checkbox"/> business <input type="checkbox"/> professional <input type="checkbox"/> student <input type="checkbox"/> other, specify: _____
31. How old is your husband/father of the child?	_____ years <input type="checkbox"/> do not know
32. How many completed years of schooling have your husband/father of the child had? ( <i>exclude repeated years and pre-school</i> )	_____ years <input type="checkbox"/> do not know
33. What does your husband/father of the child do for a living? ( <i>only tick one</i> )	<input type="checkbox"/> farmer <input type="checkbox"/> business <input type="checkbox"/> skilled worker <input type="checkbox"/> unskilled worker <input type="checkbox"/> service

	<input type="checkbox"/> official <input type="checkbox"/> professional <input type="checkbox"/> unemployed <input type="checkbox"/> student <input type="checkbox"/> other, specify: _____
34. Head of household	<input type="checkbox"/> father of the child (skip to 37) <input type="checkbox"/> mother of the child <input type="checkbox"/> father-in-law <input type="checkbox"/> mother-in-law <input type="checkbox"/> other, specify: _____
35. If head of household is another than the father of the child: age of head of household	_____ years
36. If head of household is another than the father of the child: how many completed years of schooling does head of household have?	_____ years
37. Do you own the house you live in?	<input type="checkbox"/> yes <input type="checkbox"/> no, rent the house <input type="checkbox"/> no, house of my parents <input type="checkbox"/> no, house of spouse's parents <input type="checkbox"/> no, other, specify: _____
38. What are the walls of your (main) house made of?	<input type="checkbox"/> mud brick <input type="checkbox"/> mud with wood <input type="checkbox"/> cement <input type="checkbox"/> timber <input type="checkbox"/> other, specify: _____
39. What is the roof of your (main) house made of?	<input type="checkbox"/> thatched (dried grass, mud) <input type="checkbox"/> iron sheets <input type="checkbox"/> other, specify: _____
40. What is the floor of your (main) house made of?	<input type="checkbox"/> mud <input type="checkbox"/> stone <input type="checkbox"/> cement <input type="checkbox"/> other, specify: _____
41. How many people live in your household? ( <i>ask for each age group by reading the groups, then count the total number</i> )	_____ 0-5years _____ more than 5 years, less than 18 years _____ more than 18 years _____ total
42. How many rooms do you have in your house?	_____ (number)
43. How many beds do you have?	_____ (number)
44. What is the main fuel for lighting in your house?	<input type="checkbox"/> candle light <input type="checkbox"/> kerosene lamp <input type="checkbox"/> gas light <input type="checkbox"/> electric light <input type="checkbox"/> other, specify: _____
45. What is the main fuel for cooking in your house?	<input type="checkbox"/> wood <input type="checkbox"/> kerosene <input type="checkbox"/> charcoal <input type="checkbox"/> gas

	<input type="checkbox"/> electric <input type="checkbox"/> other, specify: _____
46. What is the source of drinking water?	<input type="checkbox"/> stream/river/dam <input type="checkbox"/> well <input type="checkbox"/> spring <input type="checkbox"/> tap water <input type="checkbox"/> other, specify: _____
47. What kind of toilet do you have?	<input type="checkbox"/> pit latrine <input type="checkbox"/> flush toilet <input type="checkbox"/> other, specify: _____
48. Does your household own any of the following items?	<input type="checkbox"/> radio <input type="checkbox"/> bicycle <input type="checkbox"/> sofa <input type="checkbox"/> lamp <input type="checkbox"/> cupboard <input type="checkbox"/> tv <input type="checkbox"/> mobile phone <input type="checkbox"/> refrigerator <input type="checkbox"/> car/truck <input type="checkbox"/> motorcycle/scooter
49. How many of the following animals/birds do you have in your home? ( <i>if don't know exactly, give proximities</i> )	<input type="checkbox"/> chicken _____ <input type="checkbox"/> goats _____ <input type="checkbox"/> pigs _____ <input type="checkbox"/> cows _____ <input type="checkbox"/> other, specify and number: _____
50. Does the household use land for farming/pastoralism	<input type="checkbox"/> yes <input type="checkbox"/> no (skip to 56)
51. If yes, how is the land used?	<input type="checkbox"/> grow maize <input type="checkbox"/> grow coffee beans <input type="checkbox"/> grow beans <input type="checkbox"/> grow bananas <input type="checkbox"/> pastoralism <input type="checkbox"/> others, specify: _____
52. Estimated area of land used for farming/pastoralism	_____ acre
53. Is the land owned or rented?	<input type="checkbox"/> owned <input type="checkbox"/> rented
54. In the past 12 months did the household spend money to purchase seeds?	<input type="checkbox"/> yes <input type="checkbox"/> no
55. In the past 12 months did the household spend money to purchase fertiliser/manure?	<input type="checkbox"/> yes <input type="checkbox"/> no
56. Did the household members eat meat the past week?	<input type="checkbox"/> yes <input type="checkbox"/> no (skip to 58)
57. If yes, how many days meat eaten the past week?	_____ days

#### IV. CLINICAL ACTIVITIES

Now I will ask you some questions about the clinic. All the questions will be related to this pregnancy

58. Have you heard about a programme at the clinic regarding prevention of mother-to-child transmission of HIV?	<input type="checkbox"/> yes <input type="checkbox"/> no
59. Did you receive infant feeding counselling at the clinic?	<input type="checkbox"/> yes <input type="checkbox"/> no (skip to 61)
60. If yes, in which form?	<input type="checkbox"/> group counselling <input type="checkbox"/> individual counselling
61. Did you get any information about HIV at the antenatal?	<input type="checkbox"/> yes <input type="checkbox"/> no (skip to 63)
62. If yes, in which form? ( <i>tick all that apply</i> )	<input type="checkbox"/> general information <input type="checkbox"/> group counselling <input type="checkbox"/> individual counselling
63. Were you offered testing for HIV?	<input type="checkbox"/> yes <input type="checkbox"/> no (skip to 69)
64. Did you ask your husband/father of the child for permission to be tested <i>before testing</i> ?	<input type="checkbox"/> yes <input type="checkbox"/> no (skip to 66)
65. Did he agree?	<input type="checkbox"/> yes <input type="checkbox"/> no
66. Did you test for HIV?	<input type="checkbox"/> yes <input type="checkbox"/> no (skip to 69)
67. Did you receive the results of the test?	<input type="checkbox"/> yes <input type="checkbox"/> no (skip to 70)
68. Did you share the result with your husband/father of the child?	<input type="checkbox"/> yes <input type="checkbox"/> no
69. If no in question 66: have you ever tested for HIV?	<input type="checkbox"/> yes <input type="checkbox"/> no
70. Did they suggest your husband/father of the child to be tested as well?	<input type="checkbox"/> yes <input type="checkbox"/> no (skip to 73)
71. Was he tested?	<input type="checkbox"/> yes <input type="checkbox"/> no (skip to 73) <input type="checkbox"/> do not know
72. If yes, did he share his test results with you?	<input type="checkbox"/> yes <input type="checkbox"/> no
73. If no in question 71, has he ever been tested for HIV?	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> do not know

#### V. YOUR RELATION TO YOUR MALE PARTNER

Now I will ask you some questions on your relation to your male partner

74. How many times has your male partner visited the antenatal clinic with you during this pregnancy?	_____ approximate number
75. Does your male partner provide you with financial support to enable you to attend to the antenatal clinic?	[ ] yes [ ] No
76. Who is the one taking the decisions when it comes to ( <i>tick the most important one</i> ) clinic attendance	[ ] myself [ ] male partner [ ] me and male partner together [ ] mother-in-law [ ] other, specify _____
77. family planning ( <i>tick the most important one</i> )	[ ] myself [ ] male partner [ ] me and male partner together [ ] mother-in-law [ ] other, specify _____
78. testing for HIV ( <i>tick the most important one</i> )	[ ] myself [ ] male partner [ ] me and male partner together [ ] mother-in-law [ ] other, specify _____
79. infant feeding ( <i>tick the most important one</i> )	[ ] myself [ ] male partner [ ] me and male partner together [ ] mother-in-law [ ] other, specify _____

## VII. YOUR RELATION TO YOUR MOTHER IN LAW

Now I will ask you some questions on your relation to your mother-in-law

80. Related to your mother-in-law; where do you live? ( <i>only tick one</i> )	[ ] live in the same compound [ ] live in the same village [ ] live in nearby village/town [ ] live far away [ ] she is not alive (skip to 85)
81. How often do you meet your mother-in-law? ( <i>only tick one</i> )	[ ] at least once in a day [ ] at least once in a week [ ] at least once in a month [ ] at least once in a year [ ] less than once in a year [ ] never (skip to 85)
82. Did you (do you) live with your mother-in-law after you had given birth to your last born child?	[ ] yes [ ] no (skip to 85)
83. If yes, for how long did you stay, do you plan to stay?	_____ (weeks)
84. What were the responsibilities of	[ ] to cook

your mother-in-law when you lived there? <i>(tick all that apply)</i>	<input type="checkbox"/> take care of the newborn child <input type="checkbox"/> to clean <input type="checkbox"/> take care of you <input type="checkbox"/> nothing particular <input type="checkbox"/> other, specify: _____
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### VIII. HIV AND INFANTS

Now I will ask you some questions on HIV and infants

85. Is it possible that the mother or the father is HIV positive, and their newborn child is negative?	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> do not know	
86. When can HIV be passed from a mother to her child? <i>(Do not read responses. When the respondent stops listing, ask: what other ways do you know? Tick all that are mentioned)</i>	<input type="checkbox"/> during pregnancy <input type="checkbox"/> labour <input type="checkbox"/> through breastfeeding <input type="checkbox"/> sexual intercourse <input type="checkbox"/> other, specify: _____	
87. If there are 10 HIV infected pregnant women, how many do you think would have babies born with HIV virus?	_____ (number between 0 and 10)	
88. Would you know the number of babies that could get infected through breastfeeding out of 10 HIV infected mothers?	_____ (number between 0 and 10)	
89. Can a mother do anything to reduce the risk of transmission of HIV to her child during pregnancy?	<input type="checkbox"/> yes <input type="checkbox"/> no (skip to 91) <input type="checkbox"/> do not know (skip to 91)	
90. If yes, what can a mother do to reduce the risk of transmission of HIV to her child during pregnancy? <i>(Do not read responses. When the respondent stops listing, ask: what other ways do you know? Tick all that are mentioned)</i>	<input type="checkbox"/> take medicine <input type="checkbox"/> use condom <input type="checkbox"/> other (specify) _____	
91. Can a HIV infected mother do anything to reduce the risk of transmission of HIV to her child during the breastfeeding period?	<input type="checkbox"/> yes <input type="checkbox"/> no (skip to 93) <input type="checkbox"/> do not know (skip to 93)	
92. If yes, what would breastfeeding mothers do to reduce the risk of the baby becoming infected with HIV during the breastfeeding period? <i>(Do not read responses. When the respondent stops listing, ask: what</i>	<input type="checkbox"/> give breast milk only and no other feeds up to 6 months <input type="checkbox"/> use condoms <input type="checkbox"/> stop breastfeeding; give infant formula/diluted cow's milk <input type="checkbox"/> take medicines	

<i>other ways do you know? Tick all that are mentioned)</i>	<input type="checkbox"/> breast care, specify: _____ <input type="checkbox"/> avoid oral thrush in infant, specify: _____ <input type="checkbox"/> other, specify: _____	
93. If you hypothetically, were HIV positive, what infant feeding option would be feasible for you? ( <i>Do not read responses, only tick one</i> )	<input type="checkbox"/> infant feeding formula <input type="checkbox"/> cow milk <input type="checkbox"/> give breast milk only and no other feeds <input type="checkbox"/> other, specify: _____	

PART 2

(Explanation to the interviewer: this is a scale from 0 - 10. 0 represents do not agree at all, 10 represents totally agree. The person being interviewed will handle the scale herself and put the marker in the position she feel is appropriate according to her opinion of your statement. For each question you will look at the back of the scale were the numbers are, and write down the exact number corresponding to where the respondent put her marker. If the respondent totally agrees it will be 10.0, if less then totally agree, the number will be less then 10.)

In this part of the interview there will be made several assumptions to you. To the assumption you can agree or disagree. If you totally agree to my postulation you put your mark at the totally agree end of the scale. If you do not agree at all you put the mark in the opposite end of the scale, at the do not agree at all end. Your opinion of my statement can be anywhere in between the two endpoints, and you put the marker in the most correct direction to you. It is your personal opinion about the statement that is important.

First, we will have a try out of the scale, and I will give you two assumptions to illustrate how this scale works:

This is a really hot day	<input type="checkbox"/>
--------------------------	--------------------------

Now, if you feel that this is a really hot day; where on the scale would you put the marker? And if the day is less hot? Not hot at all?

Ugali is my preferred staple	<input type="checkbox"/>
------------------------------	--------------------------

How do you feel? Do you totally agree? Do you like ugali, but it is not your preferred staple food? Do you not like ugali at all? Where would you put the marker to illustrate this?

**It is very important that you as the interviewer make the informant understand this. You are giving assumptions, and she has to state her opinion of your assumption. Make her move the scale herself. Make her understand that the endpoints illustrate the situation of *totally* agreement/disagreement, and that if she is not totally confident, she should illustrate this with moving the marker away from totally (less than 10/more than zero) trying at the same time to illustrate in which direction of agreement/disagreement her opinion is. Example: if she does agree more than she disagrees it is somewhere between 5-10, depending on how strongly she agrees/how confident she is about her agreement.**



**Try to make her give her opinion and avoiding using the middle of the scale (5 will illustrate neither agree nor disagree).**

**X. YOUR RELATION TO YOUR MALE PARTNER**

Now I am going to make some assertions to you about your relationship to your male partner:

94. I share all the information I receive at the antenatal clinic with my male partner?	[ ]
95. I need to do what my male partner wants me to do?	[ ]
96. I can only feed our infant in a way my male partner approves of?	[ ]
97. I would share my secrets with my male partner?	[ ]
98. I can trust my male partner?	[ ]
99. If I were very sick and confined to bed, my male partner would look after me?	[ ]
100. If my mother-in-law treated me badly, I could trust my male partner to support me?	[ ]
101. If I acted in a way I knew my male partner would disapprove of, I could be thrown out of home?	[ ]
102. If I acted in a way I knew my male partner would disapprove of, I could be punished by beating?	[ ]
103. It would be easy for me to tell my male partner that I had tested for HIV?	[ ]
104. If I were HIV positive, I would fear to disclose my status to my male partner?	[ ]

**XI. YOUR RELATION TO YOUR MOTHER IN LAW**

Now I am going to make some assertions to you about your relationship to your mother-in-law:

105. I share all the information I receive at the antenatal clinic with my mother-in-law?	[ ]
106. If I need advice on infant feeding, I can ask my mother-in-law?	[ ]

107. I need to do what my mother-in-law wants me to?	[ ]
108. I can only feed the infant in a way my mother-in-law approves of?	[ ]
109. I would share my secrets with my mother-in-law?	[ ]
110. If I were very sick and confined to bed, my mother-in-law would look after me?	[ ]
111. If my husband treated me badly, I could trust my mother-in-law to support me?	[ ]
112. Who is your primary confidant?	<input type="checkbox"/> male partner <input type="checkbox"/> sister <input type="checkbox"/> mother <input type="checkbox"/> mother-in-law <input type="checkbox"/> other, specify

Thank you very much for your cooperation.



## Appendix 6: FGD topic guides

### Mothers

We are all mothers gathered here today? Maybe you would all start by introducing yourself? (Tell us your name, where you live and number of children you have?)

Today I would like to introduce you to a young female called Mary. She is 28 years old and has been married for two years to Jacob who is 29. Recently she found out that she is pregnant. She is very happy as she has been hoping for this a long time, but at the same time she is worried. Lately, she has not been feeling well, and she is worried that she might be infected with HIV. At the antenatal clinic the nurse counsel her on HIV testing and ask if she wants to be tested. Mary is in great doubts.

1. What would you advice her to do?

Probe: If you were in Mary's situation, what would you yourself have done? What are the advantages Mary could have from taking a HIV test?

What are the disadvantages?

At the antenatal clinic the nurse ask Mary if she can ask her husband to come with her for testing.

2. How do you think Mary will respond to this?

Probe: Will she ask him? (Why/why not?) How is it for a young wife to ask her husband to come to the clinic for HIV testing? (Easy/difficult?) How do you think he will respond? Would it be possible for Mary to motivate her husband to go for testing for HIV? Many men say that it is good to go together with their wife to the clinic for testing, but in reality very few actually go: why is that? Is there a better way to make men come for testing? How do you feel about couple counselling and testing?

3. Do you think that a young couple like Mary and Jacob discuss HIV as a risk in their relationship?

Probe: do you think they discuss whether they should get tested? About how HIV is transmitted? On how to avoid transmission?

Mary decides to have the HIV test, and sadly it comes out that she is HIV positive.

4. Do you think she should/will share the results with anybody?

Probe: Who would that most likely be?

Do you think Mary will share the test results with her husband? Why? Why not? How will that be for her? (Easy/difficult?) What do you think his reactions could be? What could happen? Do you think she will share it with her mother-in-law? Why/why not?

Mary is worried for her unborn child; she is worried that she might transmit the virus to the child.

5. Is it possible to prevent the child from being infected?

Probe: What can a mother do to reduce the risk of transmission of HIV to her child?

What can she do during pregnancy? During delivery? During the breastfeeding period?  
*Only when nothing is mentioned:* Condom use during pregnancy, HIV medication to mother and child, delivery method, infant feeding method, breast care, something else?

6. Is a woman in this community able to protect herself from getting HIV?

Probe: In what ways? Can a wife ask her husband to use condoms? How will he respond? Can a wife talk to her husband about multiple sexual partners?

7. How should Mary feed her child after it is born?

Probe: What are the feeding options recommended to an HIV positive mother? What do you think is the best way for a HIV positive mother to feed her infant? Why? What about the other options? (1. Modified cow milk, 2. formula milk, 3. exclusive breastfeeding). What is the most important factor when she is going to make the choice: affordability? Acceptability – what other people will think? Sustainability – if it will be possible to stick to this method as long as needed? Safety – for the child? Involvement of family members – how will they react? Will you give them the reason why you chose this method?

8. After the child is born, Mary will decide on which way she wants to feed her infant. Is the choice of infant feeding method up to her alone, or does she have to consult others and/or accept their advice?

Probe: can a woman decide on her own which way to feed the infant? To what extent does she have to accept advice from her husband? Mother-in-law? Others? Who? Will she involve the father of the child in the decision making? What will the father of the child say? What will the reactions of the father be if she decides to exclusive breast feed? Exclusive formula feed? Not breast feed?

9. Suppose you are in charge for finding a way to make more men involved in health issues – what would you do?

Probe: What hinder men of taking part in health activities? What make men involved in health issues? What can be done to make more men involved?

What is the best suited setting to give health education to men? (At a health facility? Sessions for men only? In areas outside the health facility were men meet? In the community? Men-support groups?)

Now I would like us to discuss Mary's relationship to her mother-in-law.

Mary and Jacob live in close relation to his mother and meet her often. She is very pleased that she finally gets a grandchild. After the birth of the child, Mary moves to her mother-in-law. The mother-in-law is a traditional woman who does things in a customary way.

10. Can you describe the role of the mother-in-law in this situation?

What will be her assignments?

Probe: In your opinion, does the mother-in-law have any influence on the daughter-in-law? Can she decide what the daughter-in-law should do? Can she oppose to the advice given at the clinic? In what health issues is she most likely to get involved/involve herself? Could you describe a situation were a mother and a mother-in-law disagree? Disagree on what? How did it end?

11. If Mary decides that she will exclusive breastfeed her child and the mother-in-law wants to give the infant water; what could happen?

Probe: Can Mary prevent her from doing that? Would it be possible for Mary to exclusively breastfeed if her mother-in-law is the one looking after her in the postnatal period? How do you think the mother-in-law will respond if Mary will stop breastfeeding at an early age, let's say at 4 months?

12. What about if Mary chose to not breastfeed but use formula milk or cows milk?

Probe: How do you think the mother-in-law will respond? How much influence does the mother-in-law have on the infant feeding method Mary will choose? If Mary tells her mother-in-law not to interfere in infant feeding; how could that affect the relationship between them?

Moderator gives a short summary of what have been said

13. Did I correctly describe what was said? Is there anything I have missed? Anything you would like to add?

## Fathers

We are all fathers gathered here today? Maybe you would all start by introducing yourself?

Today I want us to discuss about health issues, especially those concerning parents with a small child like you have. The focus of the discussion will be on HIV testing, transmission of HIV from parents to the child and how it can be avoided. We will also talk about the role of the father when it comes to health issues concerning his wife and children.

1. When you talk to other men, does the topic of testing for HIV ever comes up in conversation?

Probe: would you like to discuss it with your peers? Is it something men think about? Talk about? With whom? Do you think couples discuss HIV as a risk in their relationship? Is it common for couples to talk about testing for HIV with each other?

2. Do you think it is a good idea that pregnant women test for HIV? Why? Why not?

Probe: Why do they get tested? Does a woman need to ask her husband for permission to be tested? Why? How do you think he will respond?

At the antenatal clinic pregnant mothers are tested for HIV and asked to bring their partner for testing also.

3. How can the partner respond?

Probe: Do you think he would agree? Why? Why not? In reality very few men actually do come to the antenatal together with their wife and test for HIV: why is that? Many are positive to the suggestion, they say that it is good to be tested together, but they do not come: why? They seem a bit reluctant to go together with their partner for testing. Why is that? How do you feel about the possibility to test for HIV together with your wife (couple counselling and testing)?

4. Suppose you are in charge of making more men come for testing for HIV – what would you do?

Probe: Think of a place where you yourself would go – can you describe this place? What is the most suitable setting for testing men for HIV? Together with the wife at antenatal? At the health centre? At VCT clinic somewhere else? At a place for men only? Transportable clinic that comes to areas where men gather?

5. If the pregnant mother is found to be HIV positive: how do you think her partner will react? Probe: what will be his thoughts? How will he act? Will he be supportive? How? Could he blame her? Can you think of any other responses? Can he treat her badly? How? Will he go for testing himself?

6. What can happen if one of them is positive and the other is negative?

Probe: Is it possible that one of them is negative and the other is positive? If the wife is positive and the husband is negative – how can he respond? How can they handle that?

7. Have you heard about prevention of mother-to-child transmission programme? What are the services offered at the PMTCT programme?

Probe: how can men take part in this activity? Is it possible for men to take part? What could be done to increase the involvement of men in PMTCT?

8. What can be done to reduce the chances of transmission of HIV to the child?

Probe: Do you think it is possible to prevent the child from being infected? How can the father of the child support the mother in order to reduce the chances of transmission of HIV to the child? What can the mother do during pregnancy in order to reduce the chances of transmission of HIV to the child?? What can she do during the infant feeding period? *Only when no one responds*: condom use during pregnancy, HIV medication to mother and child, delivery method, infant feeding method, breast care?

9. In other countries, and also here in Tanzania, doctors and nurses now recommend that women should breastfeed only for the first 6 months without feeding the baby anything else. Do you think that is possible here? If not, why not?

Probe: Have you heard of giving the child breast milk only and no other feeds, not even water, up to six months of age? What are your thoughts about it? Is it good for the child? Could you accept your wife to follow this?

10. What is the role of the father when it comes to infant feeding decision?

Probe: Is the choice of infant feeding method up to the mother alone, or does she have to consult others and/or accept their advice? How would you as the father involve yourself? How would you respond to her not breastfeeding even if she has breast milk? If she stops breastfeeding at 4 months even if she still have milk?

11. How can a HIV positive mother feed her infant?

Probe: What are the options? (Exclusive breastfeed? Exclusive formula feeding? Cow milk?) What does it mean that it is exclusive? Why is it important that it is done exclusively? Which option would you as the father support? Which could you object to? Why? If your partner chose to not breastfeed your child, how would you as the father react?

12. How can men take responsibility to avoid HIV infection?

Probe: Can a wife ask her husband to use condoms? How will he respond? What is your opinion about condoms? When can they be used? When can they not be used? What are your

thoughts about multiple partners? How common is it? Is it accepted that men have partners other than his wife? Has the risk of getting HIV infected changed this behaviour?

In the Kilimanjaro region grandmothers/mothers-in-law are known to be an important person in the family. The mother often moves to her mother-in-law after the child has been born.

13. What would be the role of the mother-in-law?

Probe: how will she help her daughter-in-law? In what issues does she involve herself? In what issues would you involve your mother? In what issues would you not involve her? Why? Would you involve her in clinical decisions? In the subject of HIV testing? In infant feeding?

14. Would you trust your mother to give advice to your wife about infant feeding?

Probe: Why? Why not? If there was a disagreement between your wife and your mother concerning feeding of the infant – who do you think you would have supported? If your wife wanted to exclusive breastfeed, and your mother wanted to give the child water – what could happen? If your wife stopped breastfeeding at an early age, e.g. 4 months, how do you think your mother would react? If your wife did not breastfeed at all?

Moderator gives a short summary of what have been said

15. Did I correctly describe what was said? Is there anything I have missed? Anything you would like to add?

## Mothers-in-law

We are all grandmothers gathered here today? Maybe you would all start by introducing yourself?

Today I would like to introduce you to a young female called Mary. She is 28 years old and has been married for two years to Jacob who is 29. Recently she found out that she is pregnant. She is very happy as she has been hoping for this a long time, but at the same time she is worried. Lately, she has not been feeling well, and she is worried that she might be infected with HIV. At the antenatal the nurse counsel Mary on HIV testing and she decides to have the HIV test.

1. Do you think it is a good idea that pregnant women test for HIV? Why? Why not?

Probe: What are the advantages and disadvantages? Is it important to know the HIV status? Why?

Mary get the test result and sadly it comes out that she is HIV positive.

2. Who do you think Mary will inform about the test and the result?

Probe: do you think she will tell her mother-in-law? Why? Why not? If you were her mother-in-law, how would you react if she told you she had tested for HIV and found to be HIV positive? What would be your thoughts? Would you blame her? Support her?

Mary is worried for her unborn child; she is worried that she might transmit the virus to the child.

3. Can a small child become HIV infected? How?



Probe: possible during pregnancy? Possible at birth? Possible by breastfeeding? How likely is it?

4. Is it possible to prevent the child from being infected?

Probe: What can a mother do to reduce the risk of transmission of HIV to her child?

*Only if nothing is mentioned:* Condom use during pregnancy, HIV medication to mother and child, delivery method, infant feeding method, breast care, something else? When I say prevention of mother-to-child transmission, what comes to your mind? Is there a programme at a clinic or hospital near you? What are the services offered at the PMTCT programme?

Now I would like us to discuss the role of the mother-in-law in the family. In the Kilimanjaro region she is known to be an important person in the family. Mary and Jacob live in close relation to his mother and meet her often. She is very pleased that she finally gets a grandchild. After the birth of the child, Mary moves to her mother-in-law. The mother-in-law is a traditional woman who does things in a customary way.

5. Can you describe the role of the mother-in-law in this situation?

Probe: what will be the duties and the rights of the mother-in-law?

Will the mother-in-law be involved in the feeding of the infant? How? Can Mary decide on her own how to feed the infant? Or does she have to consult others? Who?

6. As the grandmother; how are you involved in child care?

Probe: do you discuss child care with your daughter-in-law? Are you involved in any decisions when it comes to care of your grandchildren? How are you involved? Are there some areas you would like to be more involved? Do you feel included? Excluded? Is there a difference between paternal and maternal grandmothers when it comes to role in child care/power over upbringing? What is the difference?

7. Could you describe an issue over which a mother and a mother-in-law commonly disagree?

Probe: disagree on what? How did it end?

8. If your daughter-in-law chose to not breastfeed her child, how would you react?

Probe: She has milk and do not give you any reason for not breastfeeding. Would you act on it in any other way? What do you think community reactions would be? What happens with the child and the mother if the mother does not breastfeed?

9. In other countries, and also here in Tanzania, doctors and nurses now recommend that women should breastfeed only for the first 6 months without feeding the baby anything else. Do you think that is possible here? If not, why not?

Probe: Have you heard about giving the child breast milk only, not even water, for the first six months? What are your thoughts about it? Is it acceptable? Could the child stay healthy on breast milk only? Would you accept your daughter-in-law to do it?

10. In this community it has been common to give infants water. Why?

Probe: Can the child manage without water if it is breastfed? Would you want to give the child water? Could you give the child water even if your daughter-in-law did not like it to have water? Can you as the grandmother make decisions on behalf of your grandchildren? What will you do if she refuses you to give the child water or milk?

11. Think of a situation where your daughter-in-law stops breastfeeding at an early age, let's say at 4 months. How would you handle that?

Probe: she has milk, but suddenly stops breastfeeding and starts replacement feeding. What will you as the mother-in-law do? Could you accept her to stop breastfeeding?

12. In your opinion, what is the best way for a HIV positive mother to feed her infant?

Probe: Why?

Moderator gives a short summary of what has been said

13. Did I correctly describe what was said? Is there anything I have missed? Anything you would like to add?



## Appendix 7: In-depth interview guides

### Mothers

Today I want us to discuss health issues, especially those concerning the antenatal and postnatal mother. In this society a lot of people have been affected by HIV, and I would like us to discuss about HIV. Would that be okay for you?

#### HIV IN CHILDREN

1. If the pregnant mother is HIV infected – what can happen to the child?

Probe: Can a small child become HIV infected? How? Possible during pregnancy?

Possible at birth? Possible by breastfeeding?

2. How likely is it? Out of 10 babies, how many do you think will be infected?

Probe: During pregnancy? At birth? By breastfeeding?

3. Is it possible to prevent the child from being infected?

Probe: What can a mother do to reduce the risk of transmission of HIV to her child?

During pregnancy? During delivery? During the breastfeeding period?

#### PMTCT

4. During your pregnancy, how many times did you go to a counsellor at the clinic for counselling and testing?

Probe: can you describe the counselling?

5. If, hypothetically, you were tested positive, who would you inform about your status?

Probe: who would be your primary confidant /significant other? Why? What are the qualities of that person?

6. Who would you hide your results from?

Probe: Why?

7. Have you heard of giving the child breast milk only and no other feeds, not even water, up to six months of age?

Probe: What are your thoughts about it? Is it good for the child? Do you practise it yourself? Do you know someone who does? Is there any obstacles/difficulties?

8. Does it happen that a woman cannot breastfeed her child? Why?

Probe: what are your thoughts about women who do not breastfeed? What happens with the child and the mother if the mother does not breastfeed? How would it be for you? Could you have not breastfed? In what circumstances? What would have been difficult about it? Do you think anyone would oppose to it? Who?

9. What are the infant feeding methods alternatives for a woman who is HIV positive?

Probe: what are you told at the clinic? Can you tell me about the advantages and disadvantages of the different methods?

10. What do you know about mixed feeding?

Probe: Is there any difference for the child concerning the risk of HIV infection whether the mother feeds it exclusively or use mixed feeding? What?

11. In your opinion, how should a HIV positive woman feed her infant?

Probe: what is the most feasible infant feeding option for an HIV positive mother? Why? What is most important to a mother when she is HIV positive and chooses a feeding method? Reduced risk of transmission? Affordability? Acceptance? Fear of disclosure? Nutrient intake for the child? Fear of being looked up on as a bad mother? What would you yourself have chosen?

12. When I say breast care – what comes to your mind?

Probe: why is it important? How would you have handled it? What do you know about oral thrush in infant?

13. What do you know about safe sex during the breastfeeding period?

Probe: can a mother ask her husband to use condom?

14. How are you feeding your baby?

Probe: has anyone influenced your choice of feeding? Who? How? Does anyone help you feed the baby?

#### MALE PARTNER

15. Do you share the information you receive at antenatal with your male partner?

Probe: is he interested in what you are told at the antenatal? Does he accept that you follow advice you receive there? Has he visited the antenatal clinic? Has he participated in any education sessions? Does he involve himself in any other way when it comes to health issues concerning the children and you? How? Do you receive support from him? What kind of support? Can you describe a situation where your male partner has involved himself? On what subject? How was he involved?

16. If you wanted to exclusive breastfeed your child, but your male partner argued that the child needed water – what do you think would have happened?

Probe: would it be possible for you to feed your infant in a way he did not approve of?

What could have happened if you decided not to breastfeed your infant? To stop breastfeeding at an early age?

17. What do you think is the best suited setting to give health education to men?

Probe: *Only when nothing is mentioned*: at a health facility? Sessions for men only? In areas outside the health facility where men meet? In the community? Men-support groups?

18. Have you ever discussed transmission of HIV with your partner?

Probe: Can you tell me about the situation? What did you discuss? Is a woman in this community able to protect herself from getting HIV? Can a wife talk to her husband about multiple sexual partners?

19. Have you ever discussed testing for HIV with your partner?

Probe: Can you tell me about that situation? How do you feel about discussing HIV testing with your partner?

20. Did you test for HIV at antenatal?

Probe: Did you discuss this testing with your husband before you tested? What was his response?

21. Did the nurse ask if you could bring your husband for testing as well?

Probe: Did you ask him? What was his response? Do you know if he has ever tested?

22. How do you feel about the possibility to test for HIV together with your husband (couple counselling and testing)?

Probe: Would that be an option for you? Why? Why not? What are the advantages? Disadvantages?

23. Many men are a bit difficult when it comes to testing for HIV. They often say that when the wife has tested he doesn't need to because he will have the same status as her. How do you think we can make more men come for testing?

Probe: where is the most suitable location for men to be tested?

### MOTHER-IN-LAW

24. Can you describe your relationship to your mother-in-law?

Probe: Do you seek advice from her? Does she support you?

25. In the Kilimanjaro region, the daughter-in-law often stays with her mother-in-law after a child is born. Can you describe the role of the mother-in-law in this situation?

Probe: What will be her duties and rights?

26. In your opinion, does your mother-in-law have any influence on you as her daughter-in-law?

Probe: Can she decide what you should do? Can she oppose to the advice given at the clinic? In what health issues is she most likely to get involved/involve herself? Do you involve her in any health issues? Which?

27. Can you describe a situation where your mother-in-law has involved herself?

Probe: On what subject? How was she involved?

28. Could you describe a situation where you and your mother-in-law had a disagreement?

Probe: disagreed on what? How did it end? Did your husband involve himself? Do you think he would have supported you if you had a conflict with your mother-in-law?

29. If hypothetically you decided that you wanted to exclusive breastfeed your child, and your mother-in-law wanted the child to be given water: what do you think could happen?

Probe: who would have the final decision? How could she have influence on you? Could you feed your infant in a way you knew your mother-in-law would disapprove of? Would your male partner involved himself? How?

30. Think of a situation where you wanted to stop breastfeeding at an early age, lets say at 4 months, how do you think your mother-in-law would react?

Probe: who would have the final decision? How could she have influence on you?

31. If you for some reason decided not to breastfeed your newborn child – how do you think your mother-in-law would have handled that?

Probe: if she refused – what could you have done?

### Fathers

Today I want us to discuss about health issues, especially those concerning parents with a small child like you have. The focus of the discussion will be on HIV testing, transmission and how it can be

avoided. We will also talk about the role of the father when it comes to health issues concerning his wife and children.

### HIV AND CHILDREN

1. If the pregnant mother is HIV infected – what can happen to the child?

Probe: Can a small child become HIV infected? How? Possible during pregnancy? Possible at birth? Possible by breastfeeding?

2. How likely is it? Out of 10 babies, how many do you think will be infected?

Probe: Possible during pregnancy? Possible at birth? Possible by breastfeeding?

3. Is it possible that the mother or the father is HIV infected while the child is not?

4. Have you ever discussed with anyone the fact that HIV can be transmitted from a mother to her child?

Probe: who have you discussed this with?

5. Is it possible to prevent the child from being infected?

Probe: What can the parents do to reduce the risk of transmission of HIV to their child? During pregnancy? During delivery? During the breastfeeding period?

### PMTCT

4. Have you heard of a programme at the clinic called the prevention of mother-to-child transmission programme?

Probe: is there such a programme at your clinic? What are the services offered at the PMTCT programme? *Only when nothing is mentioned*: counselling about HIV? Testing for HIV? HIV drugs to mother and child? Safe delivery? Infant feeding counselling? Other?

5. In your opinion, what are the advantages and disadvantages of being tested for HIV?

Probe: reasons for testing for HIV? Is it important to know the HIV status? Why?

6. Have you ever discussed transmission of HIV with your partner?

Probe: Can you tell me about the situation? What did you discuss?

7. Have you and your wife ever discussed testing for HIV?

Probe: can you tell me about it? What did you discuss?

8. At the antenatal clinic, women are offered to test for HIV. They are also asked to bring their husband/male partner for testing. How would you feel if your partner asked you if you were willing to come for testing with her?

Probe: how would you respond? Would you accept that she tested? Would you test yourself?

9. When asked, only a few men come to antenatal with their wife to test for HIV. Why do you think it is so?

Probe: what can be done to make more men come for testing? In your opinion, what is the best suited setting for men to go for testing for HIV?

10. How do you feel about the possibility to test for HIV together with your wife (couple counselling and testing)?

Probe: Would that be an option for you? Why? Why not? What are the advantages?  
Disadvantages?

11. In your opinion, do you think people should talk openly about their HIV status or should HIV be kept as a secret?

Probe: What are the advantages and disadvantages of disclosure? What could be the consequences of disclosure?

12. If, hypothetically, you were tested positive, who would you inform about your status?

Probe: Why would you inform this/these persons? Who would you hide the result from? Why?

13. What can a father do to reduce the chance of HIV transmission from the mother to the child?

Probe: How could you as the father protect your child from getting HIV infection from its mother? How can you support the mother?

14. How can people protect themselves from getting HIV infected?

Probe: What is your opinion about condom use? Can a wife ask her husband to use a condom? How will he respond?

15. Many men have other women than their wife. Do you think the situation with the risk of transmission of HIV has changed this to any extent?

Probe: What do you think of men who have other women than their wife? How common is it? Out of 10 men, how many do you think has been unfaithful to their wife? Is it acceptable? Do you think the wife will know about it? How can she respond?

### INFANT FEEDING

16. If a mother chose to not breastfeed her child, what do you think community reactions would be?

Probe: *Only when nothing is mentioned*: is there a risk that she would be treated badly in any other way? Will people suspect her to be HIV infected?

If your partner chose to not breastfeed your child, how would you as the father react?

17. In other countries, and also here in Tanzania, doctors and nurses now recommend that women should breastfeed only for the first 6 months without feeding the baby anything else. Do you think that is possible here? If not, why not?

Probe: Have you heard about giving the child breast milk only, not even water, for the first six months? What are your thoughts about it? Is it acceptable? Would you accept that for your child? Could the child stay healthy on breast milk only? In this community it has been common to give infants water. Why? Can the child manage without water if it is breastfed?

18. In your opinion, how should a HIV positive woman feed her infant?

Probe: what is the best infant feeding option for an HIV positive mother? Why?

19. If hypothetically your wife were HIV positive – how would you like her to feed your infant?

Probe: Why? How could you support her?

### INVOLVEMENT IN HEALTH ISSUE

20. Where do you get health information from?



Probe: Would you personally like to learn more about health issues? Where is the best suited setting to give health education to men?

21. Does your partner share the information from the clinic with you? How do you feel about this information?

Probe: Have you ever visited the antenatal clinic? Can you tell me about one episode? How did you feel? Would you like to go there more? Is it possible for men to attend? What are the activities at the antenatal clinic?

22. In your family, who is the one making the decisions when it comes to

a) Clinical attendance? Can you tell her to attend/not to attend?

b) Family planning?

c) Infant feeding?

Probe: Can you describe your role as the father? The role of your wife? The role of your mother?

### THE MOTHER-IN-LAW

23. Can you describe your relationship between your wife and your mother?

Probe: Does your mother somehow support your wife? How?

24. In the Kilimanjaro region, after a child is born, women often move to the mother of the father. Can you describe the role of your mother in this situation?

Probe: What will be her assignments?

25. Can you describe a situation where your mother has involved herself when it comes to the care of your child/children?

Probe: How was she involved?

26. Could you describe a situation where your wife and your mother had a disagreement?

Probe: disagreed on what? How did it end? Did you get involved?

27. If hypothetically your wife decided that she wanted to exclusive breastfeed your child, and your mother wanted the child to be given water: what do you think could happen?

Probe: Would you get involved?

28. If your wife wanted to stop breastfeeding early, lets say at 4 months, how do you think your mother would have reacted?

Probe: would she act on it in any way? How? Would you get involved?

29. Would you trust your mother to advise your wife on issues regarding infant feeding?

Probe: why? Why not?

### Mothers-in-law

Today I would like us to discuss health issues, especially those concerning the antenatal and postnatal mother.

First I want us to discuss HIV.

### HIV

1. If the pregnant mother is HIV infected – what can happen to the child?

Probe: Can a small child become HIV infected? How? Possible during pregnancy? Possible at birth? Possible by breastfeeding?

2. How likely is it: Out of 10 babies, how many will be infected?

Probe: During pregnancy? At birth? By breastfeeding?

3. Is it possible that the mother or the father is HIV infected while the child is not?

4. Is it possible to prevent the child from being infected?

Probe: What can a mother do to reduce the risk of transmission of HIV to her child? During pregnancy? During delivery? During the breastfeeding period?

### PMTCT

5. Have you heard of a programme called the prevention of mother-to-child transmission of HIV programme?

Probe: is there such a programme at your clinic? What are the services offered at the PMTCT programme? *Only when nothing is mentioned:* Counselling about HIV? Testing for HIV? HIV drugs to mother and child? Safe delivery? Infant feeding counselling?

6. How do you feel about pregnant women testing for HIV?

Probe: What are the advantages and disadvantages? Is it important to know the HIV status? Why? What about her husband – do you think he should test? Why, why not? Do you think a woman should consult her husband before testing?

7. Have you ever discussed testing for HIV with someone?

Probe: who did you discuss it with? What did you discuss?

8. In your opinion, do you think people should talk openly about their HIV status or should HIV be kept as a secret?

Probe: What are the advantages and disadvantages of disclosure? What could be the consequences of disclosure?

### INVOLVEMENT IN HEALTH ISSUES

9. In the Kilimanjaro region grandmothers/mothers-in-law are known to be an important person in the family. Why is she important?

Probe: As the grandmother; what are your responsibilities in terms of in terms of child care? Do you offer your daughter-in-law any support? What is it?

10. Can you describe a situation where you have involved yourself when it comes to health issues regarding your grandchildren?

Probe: on what was it? How were you involved?

11. In the Kilimanjaro region, the daughter-in-law often stays with her mother-in-law after a child is born. Can you describe the role of you as the mother-in-law in this situation?

Probe: What will be your duties and rights? Will you be involved in the feeding of the infant? How? Baby-sit? Is there a difference between paternal and maternal grandmothers when it comes to role in child care/power over upbringing?

12. Do you discuss health issues concerning pregnancy, birth and infant feeding with your daughter-in-law?

Probe: Does she share any of the information from the clinic with you? How do you feel about the information from the clinic? Is there any difference between your knowledge and what they are taught at the clinic?

13. Do you give your daughter-in-law advises in health issues related to pregnancy, birth and infant feeding?

Probe: what are they?

14. Have you ever disagreed with your daughter-in-law when it comes to health issues related to pregnancy, birth and infant feeding?

Probe: can you tell me about that situation? On what was it? Have you ever disagreed on infant feeding?

15. Does it happen that a woman cannot breastfeed her child? Why?

Probe: If your daughter-in-law chose to not breastfeed her child, how would you react? She has milk and do not give you any reason for not breastfeeding. Would you act on it in any other way? What happens with the child and the mother if the mother does not breastfeed? Would you still be willing to give her postnatal services like cooking, cleaning etc? What do you think community reactions would be?

16. In other countries, and also here in Tanzania, doctors and nurses now recommend that women should breastfeed only for the first 6 months without feeding the baby anything else. Do you think that is possible here? If not, why not? Do you think it would be possible to give the child breast milk only, not even water, for the first six months?

Probe: What are your thoughts about it? Is it acceptable? Could the child stay healthy on breast milk only?

17. In this community it has been common to give infants water. Why? Can the child manage without water if it is breastfed? Would you want to give the child water? Could you give the child water even if your daughter-in-law did not like it to have water? Can you as the grandmother make decisions on behalf of your grandchildren? What will you do if she refuses you to give the child water or milk?

18. If your daughter-in-law stops to breastfeed the child at an early age, let's say at 4 months, how would you react?

Probe: she has milk, but suddenly stops breastfeeding and starts replacement feeding. What will you as the mother-in-law do? Could you accept her to stop breastfeeding?

19. Who will have the final word when it comes to decisions regarding infant feeding?

Probe: how can you as the mother-in-law influence the decision?

20. In your opinion, how should a HIV positive woman feed her infant?

Probe: what is the most feasible infant feeding option for an HIV positive mother? Why?

21. Now I would like us to discuss a hypothetical situation. If your daughter-in-law hypothetical were pregnant and found to be HIV positive:

- How do you think your reactions to that would be?
- Would you support her? Why? Why not?
- How could you support her?
- Would you advise your son to get tested? Why? Why not?

- How would you advise her to feed the infant when it is born?

## Health personnel

### **PMTCT**

1. What is your impression on the general knowledge on HIV among the mothers?  
Probe: do they know how HIV is transmitted? How they can prevent transmission? Are they aware of VCT? How is their knowledge on MTCT? On prevention of MTCT? Has there been any change in the knowledge lately?
2. Do mothers consult anyone before taking the test?  
Probe: who do they consult? How important do you think male partner support is?
3. How is your impression about disclosure of the test results?  
Probe: who do the mothers disclose to? Who do they hide their results from?
4. Are the partner offered testing as well?  
Probe: How is the response? Has there been any change to this lately? In what grade can the mother motivate her partner to have a HIV test? What can be done by the health personnel? Of what importance is it to the mothers follow up of PMTCT that the partner is tested as well?
5. What could be done to get more people tested in your district?  
Probe: location, awareness, community attitude, health personnel attitude and confidentiality?

### Infant feeding advice

6. How is the infant feeding information given?  
Probe: General information/health education? How often? Before/after testing for HIV? Before or after giving the result? Is it repeated at some point? Is there any information after giving birth? Is there any kind of follow up?
7. What are the infant feeding options given to a HIV positive mother?  
Probe: exclusive formula feeding, exclusive breastfeeding, cow milk, other? What information do you give on (can you define): 1) exclusive breastfeeding, 2) formula milk, 3) modified animal milk?
8. What do you say about the advantages and disadvantages of each of the methods?
9. Do you perform an AFASS (acceptable, feasible, affordable, sustainable, secure) assessment during the counselling?
10. What information do you give about: 1) mixed feeding, 2) breast care, 3) oral thrush, 4) safe sex during the breastfeeding period?  
Probe: how do you feel this information is understood? Followed?
11. Do you use any tools in the education?  
Probe: have you seen these (Sebalda's material)? Are they used for all the mothers? Would you like to use them?
12. In your opinion; what is the most feasible option for a HIV positive mother in the Kilimanjaro region?  
Probe: why? What has the greatest impact: economics, accessibility, whether the mother has disclosed the results or not, relationship to the male partner, family support, fear of disclosure and stigma, lack of knowledge? Is there a best way for an HIV positive mother to feed her infant?
13. What is your view on the adherence of the different feeding methods chosen during counselling session at the PMTCT clinic?  
Probe: 1) exclusive breastfeeding: barriers? Someone oppose? Water given?  
2) formula milk: barriers? Affordable? Acceptable? Safe? Someone oppose? Sustainable?  
3) modified animal milk: barrier? Affordable? Acceptable? Someone oppose? Safe? Sustainable?

How much does the success of each of the methods chosen depend on support from others – father of the child, mother-in-law?

14. What happens if the mother is not able to sustain with the method she original chose?

Probe: where can she go for help?

15. Do you feel like the woman has a choice?

Probe: as a nurse counsellor – do you feel like you are giving her the options without showing what your opinion is? Do you feel like she is able to perform an informed choice: that she after receiving the information about the advantages and disadvantages of all the infant feeding options for an HIV positive woman, she will make the choice herself? Do you support her, whatever the choice she makes is?

16. What do you think the community reactions to a mother who is not breastfeeding would be?

Probe: How could her husband react? Could her mother-in-law interfere?

17. What is peoples attitudes to exclusive breastfeeding?

Probe: Have you seen any change in this lately? How many do you think are able to succeed with exclusive breastfeeding?

18. Among HIV positive mothers you know: how do they choose to feed their infant?

Probe: what do you think is most important/have the greatest influence: the counselling on how to minimize the risk of the infant getting infected or the fear of community/family reactions?

19. Who are important person to the mother when it comes to infant feeding decisions?

Probe: herself, father of the child, health personnel, own mother, mother-in-law, friends, others?

20. Who has the final word in infant feeding decisions?

Probe: how influent is the father? How influent is the mother-in-law? Does the mother have power to make her own decisions?

21. If the mother-in-law would like to give the newborn water and the mother has decided to exclusive breastfeed; what could happen?

#### Father involvement

22. Do women have power to protect themselves from getting HIV infected?

Probe: can they ask their partner to use condoms? Can they refuse to have sex?

23. How do you feel the father's knowledge on HIV is?

Probe: compared to the mothers?

24. Is there any health education reaching men?

Probe: What is it? Where is it? How can it be improved?

25. How important is the involvement of the fathers to the mother's utilisation of PMTCT?

Probe: how is your impression of male acceptance of VCT/PMTCT? Are they included in any other way? How?

26. Would it be possible to include men at the clinics?

Probe: how could it be done? What do you think of separate health education sessions with men only?

27. Is couple VCT acceptable and feasible?

#### Mother-in-law

28. What is usually the role of the mother-in-law in the family?

Probe: What kind of influence does she have? On her son? On her daughter-in-law? Has there been any changes to this lately? Is there any difference between the urban/rural areas? Between the tribes?

29. How can we reach out to the mother-in-law with health education?

Probe: in your opinion, what is the importance of her knowledge?

## HIV-infected mothers

First I want us to discuss your experiences with HIV counselling and testing

### HIV counselling and testing

1. For how long have you known that you were HIV infected?
2. Can you tell me about how you did find out that you were infected?
3. Can you tell me about the reason why you chose to get tested?
4. Did you consult anyone before you got tested?  
Probe: who? Why? Did it influence your decision whether getting tested or not?
5. Did you ever have doubts whether you should have the test?  
Probe: what were they? What were your feelings about testing before you got tested?
6. After the test, how do you feel about your decision to have the test? What have been the advantages/disadvantages? Would you recommend others to get tested?
7. Have you told anyone about the test afterwards?  
Probe: Who are your primary confidant/significant other? Can you explain why you chose this/these person(s)? What have been the reactions?
8. Have you hid the fact that you had a HIV test for anyone?  
Probe: From whom? Why?

### Antenatal

9. Did you receive any information on HIV at the antenatal clinic?  
Probe: General information? Group counselling? Individual counselling? How do you feel about the quality of that information? Is there some way you see it could be improved?
10. Were you offered to test for HIV at the antenatal?
11. Did you receive any pre-test counselling?  
Probe: in what form: general information? Group counselling? Individual counselling? How do you feel about the quality of that information? Is there some way you see it could be improved?
12. Did you receive any post-test counselling?
13. Did they offer your partner to be tested as well?  
Probe: Did you ask him if he were willing? Did he test?
14. Have you ever discussed testing for HIV with your partner?  
Probe: Do you know if your partner has been tested for HIV? Do you think he would? Why/why not? If he has tested, do you know his status?
15. Are you involved in any support group for HIV positive people?  
Probe: what group? What are the activities of the group? How often do you meet? Has it been helpful? How?

### PMTCT

16. What are the services offered at the PMTCT programme?  
Probe: counselling about HIV? Testing for HIV? HIV drugs to mother and child? Safe delivery? Infant feeding counselling? Sebaldas material...
17. During your pregnancy, how many times did you go to a counsellor at the clinic for counselling and testing?  
Probe: can you describe the counselling?
18. How did you deliver your last born child?  
Probe: hospital? Clinic? Home? Who assisted you? Did they know about your HIV status? Did they talk about it? What did they say?
19. Have you received any medication for HIV?

Probe: has there been any difficulty? Have you hid the fact that you received HIV medication from someone? Who? Has someone rejected the use of HIV medication? Who?

20. Has your child received HIV medication?

Probe: has there been any difficulty? Has someone rejected the use of HIV medication? Who?

21. Has there been any problem with follow-up of the PMTCT programme?

Probe: if yes, what have been the obstacles? Do you see how it could be improved?

22. Have you experienced stigma related to participating in PMTCT?

Probe: in which way? From whom? Have you ever been afraid that participating in the PMTCT programme could disclose your HIV status?

23. Has the father of the child been involved in the PMTCT programme at any point?

Probe: How? Has he been aware of you participating? Did he at any time participate himself? What can be done to include the fathers?

### Infant feeding

24. Have you received any information on infant feeding?

Probe: Where? What was the information? Are you satisfied with the information you got? Were you given different infant feeding choices? What were they? Were you advised to choose a particular infant feeding method? Do you feel like you had a choice?

25. Have you asked someone for advice on infant feeding?

Probe: who?

26. Who makes the decision on how to feed your child?

Probe: who influence your choice? Male partner, mother-in-law, own mother, health personnel, peers, others? How much impact do they have?

27. How are you (planning to) feeding your child?

Probe: Traditional mixed feeding? Exclusive breastfeeding? Breast milk substitutes? Cow milk. Other?

28. Why did you choose this feeding method?

Probe: *Only when nothing is mentioned:*

Most feasible, been advised to at the PMTCT, most acceptable, been told to by father of the child, been told to by mother-in-law, been advised to by others

29. Have your HIV status influenced your infant feeding decision?

Probe: in what way?

30. How confident are you that will manage to sustain this feeding method?

Probe: what can be the obstacles?

31. Have you received any kind of social support? Follow up from the clinic?

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12<sup>th</sup> November 2007

Eli Fjeld Eli  
University of Bergen  
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MUHAS  
Po Box 65001  
Dares Salaam

**CLEARANCE CERTIFICATE FOR CONDUCTING  
MEDICAL RESEARCH IN TANZANIA**

This is to certify that the research entitled: The role of male partners and mother-in-law in the prevention of mother to child transmission of HIV. (Fjeld E ), whose Principal Investigator is Eli Fjeld Eli, has been granted ethics clearance to be conducted in Tanzania.

The Principal Investigator of the study must ensure that the following conditions are fulfilled:

1. Progress report is made available to the Ministry of Health and the National Institute for Medical Research, Regional and District Medical Officers after every six months.
2. Permission to publish the results is obtained from National Institute for Medical Research.
3. Copies of final publications are made available to the Ministry of Health and the National Institute for Medical Research.
4. Any researcher, who contravenes or fails to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine.

Name: Dr Andrew Y Kitua

Name: Dr Deo M Mtasiwa

Signature

Signature

CHAIRMAN  
MEDICAL RESEARCH  
COORDINATING COMMITTEE

CHIEF MEDICAL OFFICER  
MINISTRY OF HEALTH, SOCIAL  
WELFARE

CC: RMO  
DMO





**TUMAINI UNIVERSITY**  
**KILIMANJARO CHRISTIAN MEDICAL COLLEGE**  
P. O. Box 2240, MOSHI, Tanzania

**ETHICAL CLEARANCE CERTIFICATE**

No. 201.

For Research Proposal No. 234.

Title: THE ROLE OF MALE PARTNERS AND MOTHERS-IN-LAW IN THE  
PREVENTION OF MOTHER-TO-CHILD TRANSMISSION OF HIV.

Proposed study area: KCMC.

KCMC P. 1. /Counterpart: DR. RACHEL MANONGI.

Duration of Study: ONE YEAR

Approved period: 22<sup>ND</sup> NOVEMBER, 2007 – 21<sup>ST</sup> OCTOBER, 2008.

Approved by KCMC Research Ethics Committee on 28<sup>TH</sup> SEPTEMBER, 2007.

Beatrice Temba.  
**SECRETARY**

Dr. F. W. Masha.  
**CHAIRMAN**

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(COSTECH)

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*In reply please quote: CST/ RCA 2007/93/1931/2007*

**Date: 29<sup>th</sup> November 2007**

Director of Immigration Services  
Ministry of Home Affairs  
P.O. Box 512

**DAR ES SALAAM**

Dear Sir/Madam,

**RESEARCH PERMIT**

We wish to introduce to you **Eli Fjeld** from **Norway** who has been granted a research permit **No. 2007-388-NA-2007-93** dated **29<sup>th</sup> November 2007**

The permit allows him/her to do research in the country **“The Role of Male Partners and Mother’s in Law in Prevention of Mother to Child Transmission of HIV”**

We would like to support the application of the researcher(s) for the appropriate immigration status to enable the scholar(s) begin research as soon as possible.

By copy of this letter, we are requesting regional authorities and other relevant institutions to accord the researcher(s) all the necessary assistance. Similarly the designated local contact is requested to assist the researcher(s).

Yours faithfully

H. M. Nguli

**for: DIRECTOR GENERAL**

- CC:**
1. Regional Administrative Secretary: **Kilimanjaro**
  2. Local Advisor: **Dr. M. Malecela, NIMR, P.O. Box 9083, Dares Salaam.**
  3. Co-researcher: **None**



**Errata**



**Errata for  
“The mother, her confidants and the prevention  
of mother-to-child transmission of HIV (PMTCT)  
services in the Kilimanjaro region, Tanzania”**

**Eli Fjeld Falnes**



Thesis for the degree philosophiae doctor (PhD)  
at the University of Bergen

*Eli Fjeld Falnes*

(signature of candidate)

A handwritten signature in black ink, appearing to be 'Eli Fjeld Falnes', written over a horizontal line.

(signature of faculty)

9.8.2011

## Errata

### Thesis

Page 6, Paper III: The paper has been published during the period from submission to defence and “Submitted” should be replaced with: *BMC Public Health 2011*, 11:551

Page 18, second paragraph: 2007 should be corrected to 2006 and the sentence should read: “During these years there has been a change from the 1992 guidelines recommending that HIV-infected mothers should breastfeed in countries with high infant mortality [38], to an increased focus between 1998-2006 (...)”

Page 19, “Infant feeding counselling”: Form should be corrected to from and the sentence should read: “However, this counselling has been suffering from problems associated with the frequent shifts in the policy and lack of time to follow up the new guidelines [37].”

Page 39, third paragraph: The principal investigator should be corrected to me and the sentence should read: “Interviews conducted in English were transcribed by me.”

### References

Reference number 106 and 107 are referring to the same document. Reference 106 should be omitted.

### Papers

Paper I, Table 4: In the heading the figure 428 should be replaced with 426 and the heading should read: “Table 4 PMTCT practice of the 426 surveyed mothers by type of clinic attended”

Paper I, Table 5: Number of siblings: the last subcategory should read:  $\geq 2$

Paper III, page 5, second paragraph: Study aim 1 should read: “expectations and experiences related to the influence of mothers-in-law on disclosure of HIV positive status and choice, and adherence to infant feeding method”